



Chief Minister
Treasury and Economic Development Directorate
ACT Government

Email: budgetconsultation@act.gov.au

Health consumer priorities for 2020-21 budget

Thank you for the opportunity to provide input into the preparation of the ACT Budget for 2020-21.

The Health Care Consumers' Association (HCCA) is both a health promotion charity and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA is a member-based organisation and for this submission we consulted with our members and other member organisations in the development of this input.

Please find attached the following submissions:

- Individual Advocacy
- Inpatient palliative care at Canberra Hospital
- Care for older people in emergency departments

HCCA has identified a growing need among health care consumers for support when trying to have their voice heard, including when expressing concerns or making complaints. Over the past 12 months, we have gathered evidence and assessed the need for individual health advocacy in the ACT. A detailed proposal forms part of our submission (attached).

Thank you for this opportunity and we look forward to discussing these proposals with the relevant areas. This is a public submission and HCCA is happy for the submission relating to care of older people and inpatient palliative care publicly available. We do not want the detail proposal for individual advocacy to be made public at this time.

Yours sincerely

A handwritten signature in black ink, appearing to read "Darlene Cox", is written over a light blue rectangular background.

Darlene Cox
Executive Director

October 2019

Inpatient palliative care at Canberra Hospital

The Health Care Consumers' Association (HCCA) has long advocated to increase the range and quality of palliative care services available to residents of the ACT and surrounds. Our membership and the research we undertook in 2017 clearly indicate the need to improve the consumer experience of dying while a patient of the Canberra Hospital. Therefore, HCCA strongly supports the establishment of an Inpatient Palliative Care Unit at the Canberra Hospital.

In 2017, we gathered the stories of 16 people who had cared for a loved one who received palliative care in a variety of settings – home, hospital and hospice – and one person who had received palliative care at home and was receiving palliative care in the Canberra Hospital at the time of interview. While HCCA's research focused on home-based palliative care, we gathered much insight about consumers' experiences while in hospital. Several of these experiences were less than ideal, and we were able to identify specific opportunities to improve the safety and quality of palliative care in the hospital sector. Our overall research found consumers want person-centred palliative care and carers need more support.

The experience of dying is clearly influenced by the location, but the quality of care is the determining factor. Many participants gave examples of the unsuitable environments in which their loved ones were located. These places were variously shared, noisy and public. The physical environment in which consumers find themselves at the end of life can facilitate or hinder the process, as explained below.

I think dying in a hospital, if it's not a result of a car crash or something, is really a very poor option... For her, it was about having the space she needed to prepare herself for death and for the rest of us, particularly me, it was about making that space, creating the environment around her that she needed to be able to do what she needed to do. (Participant 3)

We see that there is an opportunity to improve the experience of consumers who die while in hospital with the provision of specialist palliative care workers and a dedicated space that facilitates the palliative approach.

Towards the end-of-life it is important to focus on what is important to the person dying and those supporting them. Routine observations and unnecessary tests are of no use to the dying person and can indeed be damaging by interrupting their rest, introducing stress, and limiting the time they have to share with loved ones.

Our research suggests that hospital staff have variable and often unsatisfactory understanding of the palliative approach. We heard stories about clinicians insisting on pursuing treatment with little possibility of success, sometimes in direct contradiction to the consumer's expressed wishes. We also heard that consumers had infrequent access to specialist palliative care nurses and physicians while in hospital.

The full report, *Consumer and Carer Experiences and Expectations of Home-Based Palliative Care in the ACT*, can be found at <https://bit.ly/2D1dYxr>.

HCCA would welcome the addition of specialist palliative care workers and a dedicated space that facilitates the palliative approach.

Care for older people in Emergency Departments

We are very aware of the growing numbers of older people in Canberra and the region and the challenges this brings to the healthcare system. Older people visit emergency departments (EDs) at comparatively higher rates than people under the age of 65 and often present with multiple chronic conditions and are at increased risk of polypharmacy and delirium. This year members have raised with us issues about their experience of care in the emergency departments at Canberra Hospitals. We consider that the ACT Government can do more to ensure services are designed for the most frail and vulnerable.

Our Heath of Older People Consumer Reference Group has considered this matter this year. We have reviewed the experience of NSW and US hospitals where policies and processes were introduced to care for older people in emergency departments. This is often referred to as Geriatric Streaming. This has demonstrated better health outcomes and increased patient satisfaction, higher rates of post discharge independence, fewer re-presentations, lower admission and readmission rates. We support the introduction of Geriatric Streaming in Emergency Departments.

The Capital Health Network are supportive of this and have stated their support for Geriatric Streaming in their Needs Assessment 2017 (1) and also in their Budget Submission (2) last year.

The concept of a geriatric emergency department has developed in the past decade – particularly in the Unites States – as hospitals recognise that one size ED care does not fit all. The needs of older people are not being met. Separate spaces are within emergency departments are preferred to support models of care that meet the needs of older people. This includes things such as thick mattresses, quieter and less frenzied environments, use of lighting and sound proofing and ensuring spaces are family friendly. HCCA is advocating for these things in the SPIRE development but there is a need in the short to medium term to address this.

We know that our EDs are experiencing increasing pressure with more presentations and emergency admissions. This demand can lead to a delay in access to available inpatient beds and other resources to meet this demand. This mismatch places pressure our publicly funded health services to provide timely access to care.

This is something that warrants investment.

- (1) Capital Health Network Budget submission from 2018
https://www.budgetconsultation.act.gov.au/_data/assets/pdf_file/0014/1121009/29.-Capital-Health-Network-2018-19-ACT-Budget-Consultation-Submission.pdf
- (2) Capital Health Network needs assessment (November 2017)
<https://www.chnact.org.au/sites/default/files/ACT-PHN-Core-and-Mental-Health-Needs-Assessment-reporting-template.pdf>

Individual Advocacy in the ACT

HCCA proposes that the ACT Government fund a project to scope, pilot and evaluate a broad-eligibility consumer health advocacy service for the ACT, to meet significant unmet community need.

HCCA proposes that the service model be developed in consultation with health care consumers and health services. However, at a minimum the pilot service will provide 9am to 5pm (Monday to Friday) telephone support, and in-person advocacy based at the HCCA offices in North Canberra with capacity to travel to public locations including health services, as required. The scope of work will include supporting people to:

- understand and act on their health rights,
- access health and other necessary services,
- receive and understand health information,
- navigate health services,
- make health decisions,
- understand and consider alternative options when not satisfied with their care
- participate in feedback and complaints resolution processes, and
- increase their self-advocacy confidence and skills.

HCCA proposes to draw on and adapt the successful health advocacy model implemented for over a decade by the Health Consumers' Council of Western Australia (HCCWA) with support from the West Australian Government. This model has been in place for more than a decade. This project is an opportunity for the ACT to adopt a nationally leading model of health advocacy that supports consumer health literacy and shared decision-making.

There is currently no health-specific, broad-eligibility, community-based individual advocacy service in the ACT. Many people who require advocacy support are ineligible for existing community-based services, which are targeted to the needs of specific groups. Even with restricted eligibility criteria, these services currently operate over capacity. This indicates there is significant unmet need for health advocacy. HCCA routinely receives unsolicited requests for health advocacy from members of the public. We currently have capacity to respond in a limited way by providing general information, referral to other services and occasional individual advocacy support that is unfunded.

Demand for health advocacy will continue to grow in coming years in the ACT due to trends including population growth, increasing complexity of health care, and the higher proportion of people in the ACT and region living with one or more long-term conditions, including chronic, complex and terminal conditions.¹

Health advocacy delivers highly desirable outcomes for health services, health care consumers and professionals, including:

- Increasing public trust in health services
- Driving quality improvement in health care

- Assisting health care services and professionals to demonstrate their achievements against accreditation and professional standards
- Making health services more responsive to feedback and complaints
- Increasing people's health literacy, ability and confidence to advocate for themselvesⁱⁱ
- Reducing health inequality by assisting vulnerable people to use the health system and resolve health issues.ⁱⁱⁱ
- Reducing individuals' need to use government and government-funded services and processes, freeing these for other users.^{iv}

Independent evaluation of Western Australia's health advocacy service found it delivers outcomes including:

- Care plans that better reflect consumer concerns and priorities
- Better consumer understanding of their care and treatment plans
- Prevention of instances in which health care rights may be violated or ignored, and
- Promotion of positive rights including access to health care and welfare services.^v

A key role of advocates is to assist consumers to communicate their needs, preferences and points of view to health professionals.^{vi} A substantial proportion of consumer feedback and complaints relate either directly or indirectly to communication with clinicians: this is the case across Australia and internationally.^{vii} Advocates assist to prevent and resolve these issues.^{viii}

Delivery of this proposed service by a community organisation such as HCCA offers a cost-efficient way of achieving these outcomes for health consumers. HCCA could leverage the strong relationships it has with consumers, community groups and ACT health services. If supported, this project will enable HCCA to extend and formalise the individual advocacy our organisation currently undertakes on a limited unfunded basis, when there is no other organisation that can adequately assist the consumer.

A detailed proposal has been submitted separately.

ⁱ ACT Health 2018. *Healthy Canberra, Australian Capital Territory Chief Medical Officer's Report 2018*. ACT Government, Canberra ACT.

ⁱⁱ Maylea C et al Evaluation of the Independent Mental Health Advocacy Service (IMHA), Final Report March 2019, Social and Global Studies Centre, RMIT University

ⁱⁱⁱ Barnes D and T Brandon Independent Specialist Advocacy in England and Wales: Recommendations for Good Practice, Monograph, University of Durham 2002

^{iv} Daly, A, G Barre and R Williams. September 219 A cost benefit analysis of Australian independent disability advocacy agencies. Disability Advocacy Network Australia

^v Stomski, N, P Morrison, M Whitely and P Brennan. (2017). Advocacy processes in mental health: a qualitative study. *Qualitative Research in Psychology*, 14:2, 200-215, DOI: 10.1080/14780887.2017.1282567

vi Stomski, N, P Morrison, M Whitely and P Brennan. (2017). Advocacy processes in mental health: a qualitative study. *Qualitative Research in Psychology*, 14:2, 200-215, DOI: 10.1080/14780887.2017.1282567

vii Reader, T, A Gillespie and J Roberts. 2014 Patients complaints in healthcare systems: a systematic review and coding taxonomy. *BMJ Quality and Safety* 23,8: 678-689

viii Stomski, N, P Morrison, M Whitely and P Brennan. (2017). Advocacy processes in mental health: a qualitative study. *Qualitative Research in Psychology*, 14:2, 200-215, DOI: 10.1080/14780887.2017.1282567